DOCUMENT RESUME

ED 347 466 CG 024 396

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TITLE Complications in Working with AIDS Patients in Group Psychotherapy.
PUB DATE 14 Aug 89
NOTE 12p.; Paper presented at the Annual Meeting of the American Psychological Association (97th, New Orleans, LA, August 11-15, 1989).
PUB TYPE Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Acquired Immune Deficiency Syndrome; Counseling Objectives; Counseling Techniques; Group Dynamics; *Group Therapy; *Psychotherapy

ABSTRACT

Numerous research studies have documented that for patients coping with chronic illness, social support is extremely important in facilitating adjustment to the illness. The support may come from organized therapy and self-help groups or from interpersonal relationships outside a group. However, Acquired Immune Deficiency Syndrome (AIDS) is a chronic illness with characteristics that seriously interfere with patients receiving social support of any kind. Three factors: the threat of a drastically shortened life, an unpredictable illness course, and stigma, not only interfere with AIDS patients receiving sustained social support from the outside world but can dramatically influence the process of a psychotherapy group. The factor of early death, which can impact group cohesion, can be dealt with by encouraging mourning and facilitating accurate interpretation of group process. The factors of an unpredictable illness course can impact group cohesion by helplessness, making continuity across sessions difficult, and by excessive focus on individuals. These factors can be dealt with by encouraging expression of feelings, and focusing on the present and on group process. The factor of deviancy/stigma can impact group cohesion by rejection/hatred of self and others, but can be dealt with by providing unconditional acceptance. Therapy is often a matter of helping the patient appreciate life's complexities - to enlarge his/her cognitive worldview and spectrum of emotional functioning. (ABL)

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Complications in Working with AIDS Patients in Group Psychotherapy

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Presented at the American Psychological Association annual meeting, August 14, 1989, New Orleans LA.

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Complications in Working with AIDS Patients in Group Psychotherapy[1]

Numerous research studies have documented that for patients coping with chronic illness, social support is extremely important in facilitating adjustment to the illness. The support may come from organized therapy and self-help groups or from interpersonal relationships outside a group. However, AIDS is a chronic illness with characteristics that seriously interfere with patients receiving social support of any kind. To the extent that a psychotherapy group is a microcosm of the social world, these characteristics also complicate the dynamics of a psychotherapy group, making group psychotherapy with AIDS patients different and more difficult than other group therapies. Nonetheless, when the therapist is mindful of the complications, supportive group psychotherapy can be the psychological treatment of choice for many AIDS patients. While providing social support, the group is a forum for working on other important psychological issues.

Distinctive factors of AIDS and their impact on group psychotherapy

At least three factors set AIDS apart from other chronic, life-threatening illnesses. First, although patients diagnosed in 1989 are surviving longer than those diagnosed in the earlier stages of the epidemic, AIDS patients still, on average, have a shorter survival period following diagnosis than do patients suffering from other chronic illnesses such as heart disease and most cancers. Second, the medical course of AIDS is highly variable. The alarmingly unpredictable course of the illness makes it seem to patients and their loved ones that they are riding an emotional roller coaster. Third, the majority of AIDS patients have nontraditional lifestyles stigmatized by majority culture. Homosexual orientation, intravenous drug use, and ethnic minority status are all characteristics that isolate these groups in society. In addition, there is greater social stigma attached to the disease itself. Unlike in cancer or heart disease, in AIDS there exist fears of contamination and infectivity.

All three factors--the threat of a drastically shortened life, an unpredictable illness course, and stigma--not only interfere with AIDS patients receiving sustained social support from the outside world but can dramatically influence the process of a psychotherapy group. How exactly do these complications occur? *In brief, all three factors get played out in the group in ways that seriously threaten the group's cohesion.* Cohesion, as defined by Yalom (1975), is the members'

[1] Many of the following observations are derived from the author's work as a volunteer group therapist for AIDS patients at Gay Men's Health Crisis in New York City.

attraction to the group. Initially the fact that all group members share the same diagnosis serves to unite members and promote cohesion. Universal issues that arise early in the group--which treatment regimen each member is following, which doctors are the most knowledgeable, which pharmacies have the best prices, how to get disability benefits--facilitate the development of a group spirit very quickly. But explicit discussion of the more fundamental characteristics that group members share--again, the threat of an early death, an unpredictable course of illness, and their stigmatized, deviant status in the culture--are almost always avoided in the early stages of group formation. The three factors are nevertheless present and potentially divisive. It is my contention that the successful psychotherapy group must eventually deal with these issues, not only because they are important clinicial issues that AIDS patients grapple with, but because they pose such powerful threats to the group's cohesion. In other words, if the group does not somehow manage these issues, eventually the group itself will not survive. The difficulty, of course, is that these issues cannot simply be put on an agenda for group discussion. Approaching the issues requires extreme therapeutic sensitivity, both in terms of empathy for each individual as well as an accurate reading of the group's dynamics. Some guidelines are suggested below for each issue.

Early death. The issue of death and dying is a major one for AIDS groups, but can be approached successfully only after the group has begun to coalesce. If a member tries to discuss death and dying before the group as a whole is ready, the discussion will most likely die. To a therapist, the group may seem to be in denial. It is vitally important that the therapist not interpret this as denial or rush the group into a premature discussion of death. The group is actually not yet ready to do this, for reasons I'll discuss later, nor is it particularly useful for patients newly diagnosed with AIDS to obsess about death and dying. Unfortunately, what may happen is that a death may occur before the group has coalesced. It is the early death of a group member that can be particularly problemmatic for the group.

The early death of a group member can have profound consequences on group bonding, as members can become unusually reticient to further deepen their involvements with one another. Deaths that occur later do not seem to have this effect and, in fact, can serve to deepen the group's bonding and cohesion. But particularly after early deaths, some members may begin missing sessions, as the group can become a reminder of their own fate. Even for those who continue to attend, there may be a withdrawal of emotional energy, as members are not willing to risk increased vulnerability by becoming closer to people who may not survive them. As a group member once remarked to me soon after an early death when group members were having difficulty opening up, "Look, Gil, why should I get involved with people who are only going to leave me?" In short, the group itself may become associated with death instead of life, and the attractiveness of the group to its members is decreased, thereby seriously eroding the group's cohesion.

As much as possible, the group needs to grieve the loss of a member in the usual way--talking about what they feel--which is not an entirely sad process. Mourning is difficult work at best since many of us are taught not to share these feelings. But mourning is particularly difficult and awkward if the group did not know the individual very well. Indeed, this may be the correct interpretation of the group's experience in this instance: The peculiar sadness of losing a person whom one did not have an opportunity to know. In other words, the group's awkwardness after an early death may not be that it is resisting mourning (which is a standard explanation when patients are not performing the apparent task); a more telling explanation of the group's awkward behavior is that it cannot mourn someone it did not know. This insight can be a springboard for other issues, such as members' fear about whether *they* will die without the group having known them or leaving other business unfinished.

Unpredictable course of illness. Not only is group cohesion affected by any early deaths of members, cohesion is also influenced by the unpredictable medical course of the illness. There is enormous unpredictability in the speed in which AIDS patients can become ill and sometimes die. Such unpredictability creates an intense feeling of helplessness. Some patients slowly deteriorate, and the group will often explicitly express its concern and worry, thereby preparing themselves by anticipatory grieving. During anticipatory grieving (Rando, 1986), individuals often have a conflict between a desire to get closer to the dying patient vs. a need to let the patient go emotionally. The fascinating aspect of this process when it occurs in a group is that some members will be pursuing the closeness, while others will be distancing. The therapist gets to observe what is thought of as an intrapsychic process getting played out interpersonally. On the other hand, with AIDS, apparently healthy individuals can become ill and die very quickly. In dealing with sudden unpredictable loss, anger among survivors is normal. While group members often express anger when someone drops out of the group prematurely, the group may resist expressing anger if a member drops out by dying. But the anger remains, and the therapist needs to encourage its expression, just as a therapist would help any other survivor work through sudden loss.

As with the issue of an early death in the group, the issue of the unpredictability of another member's medical state will be experienced by the group in a way that reflects each individual's personal conflict around that issue. Examining the group dynamic is a way of working on the personal issue. As the group expresses its anticipatory grieving or anger about what is happening to someone else in the group, they will also simultaneously be dealing with their grief and anger over what is happening to them.

The unpredictable medical course of AIDS also threatens cohesion by making it difficult to maintain continuity in the clinical work from session to session. A different cast of characters may be present from week to week, and absences cannot solely be attributed to resistence, but also to real-world reasons. Therefore, it is advisable not to attempt

to work on each member's long-standing characterological issues or historical conflicts. More than in other groups, the therapist must stay tuned to the here-and-now of the group process. Clinical issues that might be worked on in other group therapies, where an individual's history becomes well known over time to the members and to the therapist, cannot often be worked through in AIDS groups.

A consequence of this state of affairs is that the group members come to attach far greater importance to the therapist than is customary. Because the group's membership is so unstable at certain times, the most stable bond will be between the therapist and each member. Members may come to depend much more on the therapist than on one another. While the therapist may be forced to be more active in working with each individual both within the session and outside group meetings, it is important that the group therapist not resort to doing multiple individual therapies in a group context. Again, the therapist needs to be mindful of the group process, interpreting what is happening and helping members discuss the feelings that are getting in the way of helping one another. If the group therapist is not oriented to the dynamics of the group and instead does multiple individual therapies, the danger is that the therapist will eventually become excessively burdened by this role and either will have an unhelpful countertransferential reaction or will simply burn out.

Stigma. Finally, the stigma surrounding AIDS makes group cohesion difficult because groups ostracized by society so often come to internalize the rejection. The premise that a group of individuals might come together to accept and support one another is alien to those individuals who have internalized society's hatred. Many individuals stricken with AIDS have longstanding and legitimate concerns about stigma because their deviant status in terms of majority culture has so frequently led to rejection (Isay, 1989). Indeed, the irrational fears of infectivity by AIDS patients that the outside world often holds may seem entirely appropriate to AIDS patients filled with self-hatred. A primary benefit of group therapy is that the group can provide an experience of people accepting one another in the present, as an antidote to all the previous rejection.

Ericksonian stages as a model

Because it is usually not possible in a group to focus extensively on the historical aspects of each individual's functioning, it may be more useful to think more generally about issues that confront anyone diagnosed with a life-threatening illness. Erickson's developmental stages are very helpful in this regard for a number of reasons: (a) Erickson's (1963) stages encapsulate universal themes that laypersons as well as professionals find provocative (trust/mistrust, autonomy/shame and doubt, initiative/guilt, industry/inferiority, identity/role confusion, intimacy/isolation, generativity/stagnation, ego integrity/despair). The stages mirror fairly accurately what AIDS patients go through at different times in their adjustment to the illness. Prior to diagnosis,

the issues may have been either pretty much resolved or at least dormant, but serious illness reawakens them and requires the individual to do some reworking. (b) Developmental stages provide a sense of order to both patients and therapists. Because stages have tasks associated with them that must be mastered before growth can continue, a stage model points the way for therapist and patient alike about what is the task at hand. (c) Stage-wise notions about the problems people face are more optimistic and growth enhancing for both the patient and therapist. Ideas about stages normalize what the person is going through and also imply an end to the dilemma and the discomfort. Erickson's stages in particular are not perjorative: To say that a patient is struggling with whether he can trust others is not as perjorative as saying that the individual seems to fear he is regressing to a state of dependency.

I will discuss mostly the first two stages as they relate to working with AIDS patients because of time constraints and also because of their importance. Trust vs. mistrust is a paramount issue in a group, as well as a primary intrapsychic conflict. Trust is not innate; it develops out of experience. Although trust involves a confidence that people will be there in the future, trust is acquired by people being here now. A group experience can provide trust. The individual needs to learn that he can trust the group with his emotional experiences. Unconditional acceptance by the therapist and other group members is crucial.

I believe a chief reason why a group in the early stages of formation cannot successfully discuss death and dying is that members have not yet developed an adequate sense of trust. One does not lay out heavy issues such as death and dying until the group has successfully handled some less profound ones. Yet even when the group has acquired some cohesion and has essentially developed a basic trust of its members, a death in the group can reawaken the trust dilemma. Once when a group had experienced multiple deaths over a fairly brief period, a member--who had just previously announced that the group had become a "safe haven" for him--told about a dream he'd had: He arrived at group one evening and no one was there--neither the members nor the leaders. His fear of abandonment during the time of upheaval and transition was palpable. The trust and security he had begun to feel toward the group was being called into question.

Erickson's second stage--shame and doubt vs. autonomy--is also extremely important in AIDS groups. Much stigma and shame are attached to AIDS and to the deviant lifestyles of most patients (Tross & Hirsch, 1988; Herek & Glunt, 1988). Until shame is better worked through, the individual may not feel entitled to a better life or be able to move forward with a sense of initiative and responsibility. As the larger homosexual community went through years of shame before it found a sense of pride and self-respect, individuals may also suffer periods of self-doubt before achieving self-respect. Not only is the shame issue important in an individual's general psychological functioning, shame can directly affect the patient's compliance with

medical treatment (Backman, 1989). If the patient does not feel entitled to live, he will most probably die. As with trust/mistrust, serious illness threatens the peace that individuals previously had made with themselves regarding autonomy vs. shame and doubt: Individuals who had become comfortable with their homosexuality find themselves facing the issue of deviancy once again. Families who had been obstensibly accepting of a son's homosexuality often find themselves faced with shame and doubt once again.

Just as a group experience can help its members acquire basic trust, group psychotherapy can help its members work through periods of shame and doubt and emerge feeling stronger and more autonomous. Although the shame issue itself can be emphasized to good advantage in group discussion, the feeling of the group as a whole should be one of unconditional acceptance of all its members.

Not only are the two early developmental issues of mistrust and shame reawakened, serious illness forces the individual prematurely into developmental conflicts normally associated with advanced age. AIDS patients are frequently thrust into having to grapple with Erickson's final stage--ego integrity vs. despair. They undertake a review of their lives, and many feel they come up short. A therapist can be enormously valuable to a patient by pointing out the ways in which the patient's life has indeed been valuable and by encouraging the PWA to live now in ways that provide integrity. Moreover, people who had achieved a fairly stable identity, may find the identity threatened by the loss of role in many areas of their lives. Just as in adolescence and young adulthood when there was much role confusion, serious illness recreates a state of role confusion.

While in individual psychotherapy a therapist can help the patient stay focused on a developmental issue, in group therapy the members will almost certainly be at different developmental stages at different times. It has been fascinating to observe people at different stages interact in group with one another. Predictably, members seem to be able to help one another if they are not too far apart developmentally. It is much like Piaget's cognitive developmental stages: When a child is ready to move into a more advanced stage of thinking, the child becomes receptive to particular environmental experiences. Otherwise, the experience just doesn't take. It is a useful principle in working with AIDS patients to remind ourselves that we must be where the patient is at. Unless we can establish empathy for his place, we cannot expect to move him out of that place. If we have been there, we can more easily be empathic. If we haven't been there, we will have to work harder. Indeed, it is very difficult when a group member has developmentally surpassed where the other members are or even where the therapist is. When someone who has reached a stage of acceptance and is working toward a state of ego integrity, other members sometimes have great difficulty understanding what the person is saying. If they are close to being there themselves, they are curious and can engage in a dialogue with the person. If they are not close to the stage, they may resist what the person is experiencing. Let me give an example:

A member of the group was approaching the first year anniversary of his lover's death. They had been together 16 years, and the lover had died of AIDS one year ago. As the anniversary date approached, the patient was experiencing considerable agony. He was becoming very existential, questioning the meaning of life and whether to go on with his own. All that had been meaningful to him previously had been taken from him. He had not fully mourned the loss of his lover: A year later, the lover's clothes were still in the closets of the apartment. I personally learned a lot from this man because he was particularly articulate about what he was going through. As you might expect, his talk and the angst he was experiencing made some group members very uncomfortable. Some members were concerned about the man's risk for suicide. Some members suggested he distract himself by going to movies or getting involved again with his church. A few members listened with great respect because the man was eloquently expressing some of their own concerns. About the only intervention I made during those months was to offer support for what was happening: I said on several occasions that he was doing exactly what he should be doing, and that it was difficult. How could the group help him?

Some time later--after he had spent a weekend throwing out his lover's clothes--he announced to the group his desire to make his experience of AIDS more positive. He felt AIDS was ultimately about love and acceptance. He had felt accepted here, and that he wanted now to find ways to love and accept other people outside the group. A successful playwright, he planned to complete a story that would offer insight and hope to others. He called his elderly mother who lived out of town and told her his diagnosis. Not long afterward, he died.

Let me sum up: A psychotherapy group with AIDS patients will have its cohesion continuously threatened by factors unique to AIDS. I've discussed several ways in which this occurs: To protect themselves from further loss and vulnerability, members may close down, with the consequence that individuals are no longer available to one another. The most stable and consistent bond in the group becomes that between the therapist and each individual. While that cannot be entirely avoided, the therapist must continue to focus on group dynamics and avoid conducting individual therapy in a group context. This does not mean that the therapist cannot honor requests for individual sessions or work in other ways with members outside the group. Group cohesion is also threatened by the fact that different patients will be at different psychological stages, and it will be hard at times for others to be empathic. The therapist again may have to be more active in making sure each person receives support for where he's at.

Caveat: Therapist's loss of objectivity

Many, if not all, of these phenomena occur in all groups, whether or not their members have a life-threatening diagnosis. What makes these phenomena particularly difficult is that in AIDS groups the emotionality is almost always more extreme. Compared with other

groups, even groups where members are chronically ill, AIDS patients are likely to experience greater depression, anxiety, fear and anger. The extreme emotionality may cause the therapist to lose objectivity. Therapists need to have empathy for patients, but therapists also must distance themselves from the process in order to be helpful. In all psychotherapy formats (individual, group or family) and in all the particular theoretical orientations within those formats, all therapists have been trained to distance themselves from the content of the material at certain points and think about process. Family therapists call this taking a meta-position. A major complication in running an AIDS group is that the emotionality makes therapists forget their training--therapists get caught up in the emotional content and lose their distance and objectivity.

A primary way we as therapists lose our objectivity, in my experience and observations of other therapists, is that the extreme emotional experience of AIDS patients tend to induce in us a feeling of helplessness. Conducting an AIDS group dramatically demonstrates our own inadequacies, ineffectiveness, powerlessness and helplessness--feelings that are rarely as powerful in other psychotherapy groups. It's appropriate for therapists to have these feelings; those feelings have been induced by the group members. The question is how therapists handle them. Therapists need to talk about them with one another, as well as to use those feelings to understand the group dynamics. One risk is that therapists may act on the feelings by rushing in to save the patient. I have observed and talked with a number of AIDS therapists and believe that all of us at times respond to these powerful feelings by giving premature advice to the patient or by problem-solving for the patient. I don't think it's helpful for us always to do this. The therapist who does it consistently is conveying a message that the client is inadequate. This message does not empower the patient to help himself; it ultimately is a message that is disrespectful. Another message conveyed is that the therapist cannot bear listening to what the patient is saying. There has been a failure in empathy because empathy is too painful for the therapist. It is so much easier to problem-solve, give advice, or distract the patient from his feelings.

A well-functioning AIDS group helps the PWA gain real acceptance of the diagnosis and what is happening so that members can live maximally in the time remaining. The therapeutic mechanism that allows acceptance to occur is that the therapist accepts the patient's experiences. That is done by getting the patient to express his feelings about the here-and-now, and the therapist and other group members being able to hear him out and tolerate the feelings his talk arouses in them. This is easier said than done, since the negative affect can be so powerful that others in the room may try to escape in various ways. The task is to be able to hear where the person is at, and then working within fairly narrow limits, attempt to move him to a position of greater understanding, self-compassion, and self-acceptance. The task is to embrace his current understanding and attempt to enlarge it--not change it, but enlarge it. Therapy is often a matter of helping the

patient appreciate life's complexities--to enlarge his cognitive worldview and his spectrum of emotional functioning. But to expand someone, we've got to meet him where he's at.

Although this talk has focussed more on the difficulties of conducting a therapy group with AIDS patients, I want to close by stating that the work is some of the most rewarding clinical work I have ever done. There were many group meetings where there was such trust, such personal strength and pride, such initiative, and such integrity that group members as well as the therapists seemed to behave as though they could successfully meet any challenge. Was the group in denial on those occasions? I don't think so. I think they were expressing their humanity and celebrating how good it felt to have acceptance.

Table 1. Factors Affecting Group Cohesion in Group Psychotherapy with AIDS Patients.

Factor	*Specific impact on group cohesion*	*Clinical Guidelines*
Early death	Missed sessions Withholding	Encourage mourning Facilitate accurate interpretation of group process
Unpredictable illness course	Helplessness	Encourage expression of feelings (anticipatory grieving, anger)
	Continuity across sessions difficult	Focus on present
	Excessive focus on individuals, with therapist-patient bond strongest	Keep focus on group process
Deviancy/stigma	Rejection/hatred of self and others	Provide unconditional acceptance

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